

Finding safe and appropriate support

Guidance for PDA people



This guidance was co-produced by professionals and PDA adults with the support of PDA Society

Overview

This resource has been created by PDA adults, professionals and carers of PDA people, with the support of PDA Society. It aims to help PDA people find safe and appropriate support.

As a community that's misunderstood, PDA people struggle to find helpful and appropriate services. This can make us vulnerable to taking up services that might not be helpful (for example, because PDA isn't understood, or because the provider's understanding isn't backed up with professional expertise and/or boundaries).

We believe our community should be able to access support that helps us and doesn't harm us.

We hope this resource will help our community to identify safe practice and know what to do if services seem unsafe.

A version of this guide will be created for parents and carers, and a supplementary resource is being produced for professionals.



The illustrations in this document are intended to be gender neutral.

6. Assessing an existing relationship

What a safe relationship looks like

What if my PDA traits are hindering the relationship?

Red flag behaviours

How can I tell if behaviour is inappropriate?

What if I've decided their behaviour is inappropriate?

Seeking support for yourself

Taking steps to ensure unsafe behaviour is recognised and addressed

7. Ending a relationship

Communicating that you want a relationship to change

What if they don't react well to me ending our professional relationship?

What if they owe me money?

8. How to move on after the end of a professional relationship

Can we be friends?

Unplanned endings

Conclusion

Final note from PDA Society's CEO



Introduction

Letter from the Safer PDA Panel

Hello,

If you're reading this guide, it's likely you're looking for support, or are unsure about support you're already receiving.

PDA people can be vulnerable to putting up with harmful professional relationships for a number of reasons. PDA people:

- ◆ Are likely to avoid established ways of doing things.
- ◆ May miss social cues.
- ◆ As PDA is so misunderstood, our lived experience may have taught us to doubt our own judgement. After all, if we have been told by parents, teachers, peers, bosses and others that our inner experience isn't real, it can be hard to trust our own perception.
- ◆ Are likely to have intense, roller-coaster emotions.
- ◆ May mask our true feelings, making it hard for professionals to see our needs.
- ◆ May think of self-care as an irrelevant demand to avoid.

There is a wide range of professionals with different specialisms and skills whose support we could access, but it can be hard to identify who's the best fit. This guidance is designed to support you in navigating the whole process: from the point of deciding you want help, to ending a professional relationship safely. Sections are visually coded to make it quicker to find what's relevant to you.

We hope it's helpful.

Signed

The safer PDA panel



1. What support do I need?

A helpful start might be to work out what you need help with, how you want this help to feel, and what you want to gain from it.

If you are looking for support that meets your needs and can improve your life, without seeking to change who you are, then it is important to be clear what that help might look like. You could start by asking yourself the following questions:

What do I want help with?

As a result of this help what would I like to happen?

What professionals do I already have in my life?

What impact could the work I'm doing with them have on the thing I want help with?

What is important to me about the professional I'm seeking help from? Do they need to have particular knowledge, experiences, values or ways of behaving?

The answers to these questions will be the basis for your search for the right professional. This will also help you reflect whether a professional you are working with is helping in the way you intended.

If you want help in more than one area, it might be useful to decide which is most important to you right now, or consider employing more than one professional.



2. What kind of professional fits me best?

Now you've got an idea of what you want, you're set up to research the types of professionals available.

What a professional's title means

Regulated titles: Some titles – for example, psychologists and speech and language therapists – can only be used if the practitioner has specific qualifications and is accountable to a regulatory body (which ensures professional standards are maintained and sets clear guidance about what good practice looks like).



Self-regulatory standards: Some unregulated professionals opt into a set of standards issued by the group's professional body (for example, the British Association for Counselling and Psychotherapy). This means you can find out what standards the person has said they will adhere to. In some cases this may not be checked by the self regulatory body.

Unregulated titles: Other providers are not accountable to any regulators or professional bodies. It's their responsibility to define their own role, what they are (and are not) competent to do, and how they ensure that the support they offer is safe and helpful.

Getting a diagnosis

If you're specifically seeking support to gain a PDA diagnosis, PDA Society has produced a guide which might be helpful: pdasociety.org.uk/life-with-pda-menu/adult-life-landing/diagnosing-pda-adults

What knowledge professionals need in order to work well with PDA people

It's important to note here that not all professional bodies have a deep understanding of neurodiversity and PDA, so the practice they outline may not be suitable for PDA people. It is always OK to ask professionals to adapt their practice to your needs.

Professionals working with PDA people should try to:

- ◆ Be person centred and focus their work with you around your needs and preferences where possible.
- ◆ Communicate in a non-directive way.
- ◆ Be flexible around your changing needs.
- ◆ Take account of your sensory needs.
- ◆ Offer creative and playful ways to approach things that must be done.
- ◆ Be aware that many PDA people have co-occurring conditions and make adjustments around these too.

The clearer you can be about what adjustments are helpful the easier it will be for professionals to meet your needs.



3. Finding a professional

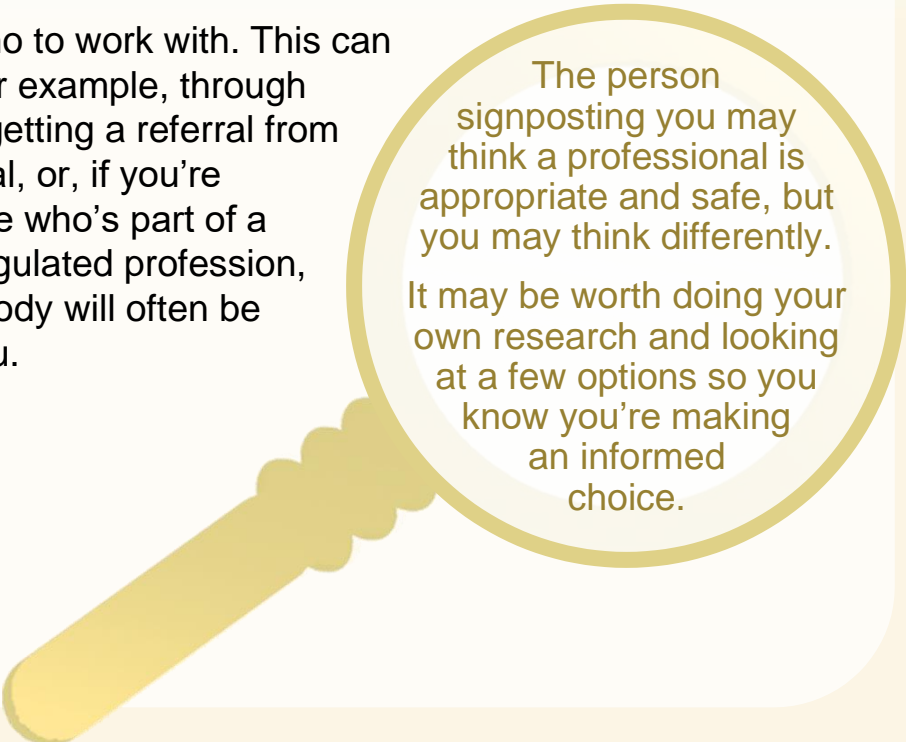
Now you've worked out what type of professional fits your needs, you're set up to find one.

If services are paid for by your local authority or health provider

There may be no choice about who you work with. However, you can ask the referrer if they're confident the professional is safe. You can also work with the professional you've been allocated to set up their service in a way that's safe and adapted to meet your needs. (This is covered in the section called Starting Safely).

If you're using your own money, have a personal budget or using Right to Choose

You can choose who to work with. This can be done directly (for example, through searching online), getting a referral from another professional, or, if you're looking for someone who's part of a regulated or self-regulated profession, their professional body will often be able to signpost you.

A large, stylized magnifying glass with a yellow handle and a circular lens. The lens is focused on the text below.

The person signposting you may think a professional is appropriate and safe, but you may think differently. It may be worth doing your own research and looking at a few options so you know you're making an informed choice.

Personal budget

This is money provided by local services (council) to pay for your social care needs, or for the needs of someone you care for.

What sort of support does it cover? Support might include someone to help you to care for your day-to-day living tasks.

Will it cover all the costs? Depending on your finances, you might have to pay some of the cost of care or support.

Who is it for? Anyone over 18 can apply for their social care needs to be assessed. This information applies to England, but there are similar arrangements in Wales, Scotland and Northern Ireland.

Who is it paid to? Some, or all, of your personal budget may be paid directly to you. Or you could nominate an advocate to look after it for you.

Alternatively, it may be paid to the council or organisation providing the service.

Is it the same as a personal budget for education? A personal budget for social care is different from a personal budget for education. However, when a young person reaches adulthood, their education budget may be redirected into a personal care plan.

Where can I find out more? Useful information and guidance about personal budgets can be found [here](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets) at: [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets)



The next step is to understand your options.

Right to Choose

The NHS will pay for a private specialist, provided they have a contract with any NHS Integrated Care Board and the cost is comparable to the NHS's usual provision.

Who is it for? This information applies to England. It can be useful if you live in an area that's short of resources, lacks a diagnostic pathway for neurodivergence, or applies outdated criteria.

How do I apply for it? You need a referral from your GP. Right to Choose doesn't give you a right to demand a referral, but you can seek a second opinion if your regular GP has decided not to refer you.

Does it have other benefits? Right to Choose can help you to reduce the wait for a service that's under-resourced locally.

Does right to choose cover everything? There are some exceptions and limitations, which are explained in guidance at: [nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs](https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs)

Now might be a good time to use "due diligence".

Making a shortlist

Due diligence means assessing whether a professional meets your needs. The amount of diligence needed depends on whether a regulatory body has already checked a provider's fitness to practise.

If the provider isn't regulated, it might be worth finding out:

What qualifications & experience they have, and how this will help them work with you.

How much their services will cost you, and what you'll get for your money.

Whether they talk about PDA in a way that leads you to believe they'll be helpful.

If they have a [DBS check](#) (disclosure and barring service), insurance and registration with the [ICO](#) (Information Commissioner's office, which upholds information rights in the public interest).

If they offer an introductory session so you can see if they're right for you.

What their terms and conditions are.

Practical information like location, frequency and timings.

A perfectly trustworthy professional might fail to meet all these criteria. For example, an organisation might not process enough data to warrant registering with the ICO, but they should be able to tell you how they ensure your private information stays private.

Anyone who has your best interests at heart will be happy to answer any of these questions.



4. Making contact

Now you've worked out what help you need, and have found a professional who seems right for you, you're all set to establish contact.

What organisations are like in real life can be different from how they appear online, so making contact with a couple of service providers before you decide who to employ might be helpful.

A person-centred professional, or organisation, will try to prioritise your unique needs.

You can get a sense of how person-centred an organisation is by getting in touch, using whichever method you are most comfortable with, and asking how they'll adjust to your needs.

You might want to know:

Do they offer a choice of ways to get in touch?

Are they available the times you need them?

Can they be flexible about changes to plans?

Is the venue accessible for you?



Now is a good time to see if individual providers are a good fit for you.

Appropriate and safe providers say if they can, or can't, meet specific needs – such as a quiet waiting space or public transport links – without blaming the person with those needs.

Taster sessions

A trustworthy professional won't put pressure on you to decide straight away. Most provide a taster session. This may, or may not, be free, but it's unlikely to involve a large upfront cost.

Taster sessions clarify if a service feels and is, or isn't, a good fit for you (for example, how accessible the service is, if you're really tired after the session, or even if the venue's next to a food shop with an off-putting smell).

It might be helpful to try sessions with more than one provider before making a decision.



5. Starting safely

Now you've made contact, and maybe had a taster session, you can get started with the professional you've selected.

To start safely, it's best to have a written agreement. This might be a formal contract or a summary which they email to you.

If your provider doesn't offer a written agreement, it's worth asking for one. This could be a simple email, covering the terms of engagement, so both sides have clarity.

Points to consider

Practical information: will meetings be:

In person, online, via phone, or a mixture?

Is there a waiting room?

Is there parking?

What software will be used for online sessions?

What happens if the connection drops?

How can you make contact between sessions if you need to?

Goals and outcomes: it's important these are things you want to work towards.

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Duration and check in points: how long do they expect the working relationship to continue? It's helpful to set a review cycle for longer working relationships to ensure progress is being made and the relationship is useful.

Fees and payments: a clear schedule of fees, how and when payment is to be made, charges for any additional services or cancelled appointments.

Cancellation process: how to advise them if you need to cancel, what they charge for non attendance and how to rebook. Last minute cancellations, or terminations of relationships, may incur costs for them.

Ending the relationship: is there a final review session? How can either party terminate the relationship early (this might need to be in writing with a period of notice).

Complaints process: ideally there'll be a separate policy that explains how to raise concerns about their service. Or they might signpost you to a regulatory body or professional association they're a member of.

Confidentiality and safeguarding: confirmation that they're registered with the ICO (the Information Commissioner's Office, which protects information rights in the public interest). How they keep your data safe and secure. In what circumstances would they need to break confidentiality if they have significant safeguarding concerns.

Supervision and reflective practice: how they ensure they have their needs supported so that, in sessions, your own needs are central to the work and process.





6. Assessing an existing relationship

Now you're working with a professional, it might be useful to know what safe –and unsafe– practice looks like.

What makes a relationship safe?

Person centred: focused on your needs and outcomes you've set.

The professional will have thought about how they have their own needs met outside your sessions so they maintain focus on you.

They'll consider how to be approachable without sharing much personal information or giving the impression you're friends.

They won't make you feel that their approval must be earned.

They'll not seek validation from you, or use your time to work through their own issues.

Professional: sessions will be delivered as originally described.

Clear, written boundaries are provided from the start, and the professional works within these boundaries for the length of your relationship, and beyond.

Clarity that the boundaries' purpose is to keep you both safe.

Contact is always about professional matters and conducted at appropriate times and places.

If contact happens at your home or theirs it's important that they show they've considered all the risks, to them and to you, should either person act inappropriately.

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Respectful: prioritising your autonomy, privacy and personal space. The provider will frequently check your feelings of safety and ask your consent for anything done to you (even if it's been done before).

Your consent should be sought for any physical contact (with an explanation of why it is appropriate), for changes in the venue or the style of sessions, and for sharing or using any information about you in any way. It will be clear that you have a choice, and that there will be no negative repercussions if you don't give your consent.

Transparent: where you feel free to share thoughts, feelings and ideas.

Records are timely, accurate and available for you to share.

No professional should ask you not to talk about what you do in your sessions, or suggest they're giving you "special treatment" you should keep quiet about.

You should be able to talk to people about anything that happens in a session with someone you're paying to help you.



person centred
professional
respectful
transparent

safe



What if my PDA traits are hindering the relationship?

Masking: Some PDA people find that their masking leads professionals to believe they haven't got any significant problems.

Situational mutism: being temporarily unable to speak, sometimes feeling physically frozen – could lead a professional to believe that the PDA person either has nothing to say, or that they're not engaging in the session.

Demand avoidance: may cause the professional to feel disrespected. For example, a PDA person may repeatedly cancel appointments. Suggestions made by the professional, such as keeping a journal, may also be avoided.

Trying to fix the wrong thing: Some professionals might assume that PDA traits – such as demand avoidance and anxiety – can and should be fixed, when this might not be appropriate.

It might be worth explaining why you reacted as you did and exploring whether this understanding can enable your professional relationship to continue. Or it might be that you, or the professional, feel that the relationship isn't able to meet your needs. There's guidance on ending relationships safely in [section 7](#).



Red flag behaviours



The following behaviours are clear red flags:

Consuming alcohol or illegal substances in, or before, a session, or suggesting you consume them.

Seeking to connect their personal social media profiles with yours.

Asking about your sex life.

Talking about their sex life.

“Diagnosing” you with conditions unless they are a diagnostic professional working within NICE guidelines.

Pushing you to talk about things that make you feel uncomfortable.

Making sexual propositions.

Touching without consent.

Touching in a way that’s not necessary for service being offered.

Repeat contacts between sessions.

Contacts of a personal nature.

Suggesting “getting together” outside of the work you’re doing.

Creating an environment where you feel you must seek their approval.

Sharing your information without consent.

Abusive or violent language.

Abusive or violent behaviour.



How can I tell if behaviour is inappropriate?

You might be unsure if a behaviour is inappropriate (for example, if they message you via social media without prior agreement).

If something happens with the provider that makes you feel confused or unsafe, it could be a good idea to talk it through with someone you trust and ask for their perspective.

It's OK to end a working relationship based on a gut feeling (you don't have to wait for something bad to happen). Equally some PDA people don't notice, or don't value their own discomfort. If you are unsure, it's always OK to ask for advice.



What if I've decided their behaviour is inappropriate?

Once you've realised that someone is working in an unsafe way you may want to:

Seek support for yourself.

Take steps to ensure unsafe behaviour is recognised and addressed.

Depending on the severity of this behaviour you may want to go through these steps in order, or if you think someone is at immediate risk of significant harm skip straight to the final step of making reports to social care and the police.



Seeking support for yourself

You might wish to speak privately to someone you trust, or contact PDA Society's enquiry line to get support and discuss what steps to take next.

Alternatively social media can be a great way to get peer support quickly. However, it might be worth considering the privacy settings on your account before you do this. What if someone takes a screenshot of what you've said? Limiting the audience can reduce the risk of someone using your words against you. You could do this by private messaging people you trust or by editing your audience on posts on your personal page.

It can be helpful to talk about your experiences by focusing on the support you need without naming the person you have concerns about.

Talking publicly waives your rights to anonymity and, in some cases, could expose you to further negative experiences, such as being trolled. Should you choose to use names you might also be at risk of being accused of libel or slander. If you're making a formal complaint: it might be worth asking how talking publicly might impact their ability to take action. If it's a criminal offence talking publicly may reduce the chances of a conviction.



Taking steps to ensure unsafe behaviour is recognised and addressed

Leave a review: Review sites offer you the opportunity to give feedback about how a service was for you. Where services have the opportunity to leave reviews this can be a safe way of sharing your experiences with limited risk to you.

Use their complaints process: If the person, or organisation, you're working with has a complaints process – and you feel safe using it – you may want to make a complaint.

Safe people and organisations welcome complaints as ways to help them think about practice and improve it. Their complaints procedure should let you know what you can expect to happen.

When deciding if it is worth making a complaint directly to the organisation or individual you've been working with you might want to consider whether they are part of an organisation or a sole trader.

A sole trader will normally respond to a complaint themselves

An organisation can make other people working for it aware of the actions that made you uncomfortable.

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Raising a concern with a regulatory body. Where you are working with someone from a regulated profession then their regulatory body will be able to decide if they are working in line with that profession's standards, and if they are not then they can take action.

Raising a concern with a safeguarding body or the police. If you are concerned that the person you are working with is acting in a way that isn't safe for you or others you can seek advice from your local authority safeguarding team. The person you speak to might be called a [LADO](#) (local authority designated officer) or a [MASH](#) team (multi agency safeguarding hub), different areas use different terms – you can find your local safeguarding service and how to contact them on [NHS England's Safeguarding app](#).

Making contact with a safeguarding team will allow you to tell someone what has happened, and they will let you know any action they plan to take, if any. They can also suggestion further steps you can take.

If you want to talk in general terms about your experience without using names this is usually OK.

It is always useful to follow a telephone conversation with these teams with an email outlining your concerns – some teams don't accept emails and ask you to fill in an online form. Where this is the case they should email you a link to this form.

If you think a criminal act has taken place. Contacting the police about your concerns will be helpful. They will explain to you what information they need from you and what you can expect to happen next.



7. Ending a relationship

Now you're ready to end a relationship that doesn't feel right for you, what's the best way to do it?

Ending a professional relationship early can be a difficult and sensitive matter. The approach you take will depend on the nature of the relationship and the reasons for ending it.

Planned endings will likely have been covered in the working agreement you put together at the beginning of the relationship.



Unplanned endings are ones which don't happen in the way you agreed at the beginning of your work together. These could happen because of a change in circumstances or because you no longer want to work with a person. Unplanned endings caused by the provider should have been set out in your working agreement. As you're not the one ending the relationship the content of this section is unlikely to be for you. The next section, ['how to move on'](#), may be helpful.

Communicating that you want a relationship to change

If you feel it's safe to do so it can be helpful to let the person know you're going to stop working with them (particularly if you are hoping to get a refund). You don't have to give a reason. It can be helpful to communicate via email so you have a record. You may want to request a receipt that the email has been received and read.

If you wish to have no further contact with this person, you could state this in the email.

You may want the person to know why you are no longer working with them. If so, it's helpful to use factual, non-emotive language to describe your experience and what's been unhelpful for you. You don't need to do this unless you want to.



What if they don't react well to me ending our professional relationship?

If you find their response to you trying to end contact with them threatening or upsetting then follow the instructions in the raising concerns section.



What if they owe me money?

If you are ending a professional relationship because they did not do what was agreed, then you can ask for some, or all, of your money back. This might be because the work was not done at all, or because it was very different from your initial agreement.

At this stage this is a commercial dispute and the first step is to ask the person or organisation for a refund and give them a reasonable amount of time to respond.

If they don't respond with what you believe to be a fair offer, you could choose to pursue a case through the small claims court. Information about this can be found here: [gov.uk/make-court-claim-for-money](https://www.gov.uk/make-court-claim-for-money)

This process can be stressful and so you might want to consider carefully whether the process is justified by the financial reward.



8. How to move on

It might now be worth thinking about how you can plan for and manage moving forward

When a professional relationship ends, it's a change for both you and the professional.

If the ending was planned, you hopefully had time to prepare and discuss it with the person you worked with.

You may have had a plan in place for this moment, which might include:

How you identify what you've learned.

What you'll do to hold onto positive gains from your time together.

What to do if you need this person's help again.

Can we be friends?

A safe professional will recognise the likelihood of a power imbalance in your relationship, so moving from a professional relationship into friendship is unwise.

Some regulated professionals have guidelines about this. It's possible to become friendly with people you've worked alongside but safe professionals will discourage it unless a significant amount of time has passed, and you have social connections not attached to the work you did together.



Unplanned endings

If the ending was unplanned because something went wrong or you felt unsafe, your safety should come first.

It might be helpful to take time to process and understand what happened, to identify what you've learnt, and consider what you can do to minimise long-term impacts from the unsafe behaviour of the practitioner. You might choose to go through this reflection process with someone you trust.

You may also have reported your experiences to other organisations who can help, and it can be valuable to reflect on whether you are satisfied with any actions taken.

When you're ready, you may identify something else you want help with, and feel able to start the process again.



Actions you can take to limit future contact with that person

If you don't want any further contact with the practitioner, there are ways to limit their ability to communicate with you.

But there might be a few things to consider first:

If you were referred to them by a statutory provider, you might need to let the person who referred you know you're ending the relationship so that they communicate directly with you (and not through this person).

If the person has power over your circumstances (for example, if they're a court-assigned social worker) you might need to negotiate with the body who assigned them to you so you can agree what reasonable communication looks like.

If you're seeking a refund, an apology or a response to a complaint, you could ask a person you trust if they'd be prepared to communicate on your behalf by proxy.

Once this is done, and any agreements around statutory contact has been made, you can take action to limit how they can contact you:

Block numbers and profiles on your phone, email and social media

Set a "rule" in your email inbox to forward messages from them to someone else, or generate an automatic reply.

Block any triggering words or phrases (including their name) on your social media.



Conclusion

Once your work with a professional is completed whether it ended because you had reached your goals together or for another reason, it can be helpful to reflect on the process you've been through.

If you've used this guidance for the whole process it might be worth going back and reflecting on your answers to the questions in section one. Did you achieve what you hoped to? What have you learnt about what works for you? Is there a way that learning can serve you in the future?

Perhaps what you've learnt will be useful the next time you seek support from a professional and are going through this process again.

We hope you've found this guidance useful.

Signed

The safer PDA panel



A final note from Elizabeth Archer, PDA Society's CEO

I'd like to finish this guidance with a note of thanks.

Firstly – Thank you to you for reading this guidance. I hope it's helpful.

Secondly – a big thank you to the volunteer members of the Safer PDA Panel who have worked on this document unpaid over the last 6 months because they want it to be easier for PDA people to access support that is appropriate and safe.

The panel came about after PDA Society noticed a trend; we were being asked regularly about how trustworthy different providers were – and it was difficult for us to give an answer. We are a small charity with limited capacity, and we realised that we couldn't responsibly answer these enquiries without redirecting resources away from other types of support, training and information which is desperately needed.

But we also knew we couldn't do nothing. PDA people are already misunderstood and under-served, and so it is vital that the support services which are available can meet their needs.

We put a call out for PDA adults, parents and carers of PDA people and professionals with knowledge of safeguarding, and asked them to volunteer to join a panel. With PDA Society acting as Secretariat, these volunteers have worked collectively to put together a practical and accessible resource. We hope that this makes it a little easier for PDA people and their carers to find safe services, and to know how to respond if something goes wrong.

This guidance represents 6 months of work by a group of committed volunteers with a shared purpose – to make accessing services easier and safer for PDA people. Thank you to all the members.